

Discussion paper

Family initiated escalation of care for the deteriorating patient in hospital: Family centred care or just “box ticking”



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ABSTRACT

Family centred care is a shared belief that a child's emotional and developmental needs are best met when the health system involves the family in planning, delivery and evaluation of care. The important role that families contribute to health care outcomes is emphasised throughout the National Safety and Quality Healthcare Service (NSQHS) Standards. An emerging component is the family's contribution to Rapid Response Systems (RRS) through the early detection of patient clinical deterioration. This initiative has been driven, in part, by a number of high profile paediatric cases where it was identified that healthcare providers did not appropriately respond to families' concerns, resulting in patient deaths. This paper draws together the synergies between family centred care concepts, the NSQHS Standards, and the progress made to date in developing a family initiated process for escalating care with specific reference to paediatric acute care.

A number of programs have been developed to guide implementation of family escalation of care. Measures of effectiveness of implementation have mainly focused on policy and process without first understanding barriers or facilitators through engagement with stakeholders and environmental assessment. Two recent reviews have not identified any rigorous attempts to evaluate implementation and only 11 reports are cited across these reviews to date. Evaluation of effectiveness of this complex intervention should take into account process measures of fidelity, dose and reach. There is also a need to assess the impact on families, particularly within a diverse cultural mix. An agreed definition for a paediatric RRS patient outcome measure is essential in evaluating the impact on patient safety and quality. Without this systematic evidence informed knowledge translation approach, then it would appear that progress in implementing family initiated deterioration of condition processes is more about meeting the NSQHS Standards – ticking the box – than genuine engagement with families.

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1. Introduction

Family centred care is a well-established model of care in the paediatric healthcare setting. It is centred on the belief that a child's

emotional and developmental needs are best met when the health system involves the family in planning, delivery and evaluation of care.¹ In the adult setting patient and family centred care is also now becoming a priority.² The recent publication of the ACCCN Position Statement, Partnering with Families in Critical Care³ articulates the expected standards for patient and family care in the context of critical care nursing. This represents a paradigm shift from when critical care nurses found it too demanding to meet the needs of families in adult settings.⁴ As recently as 2008, it was reported⁵ that Australian intensive care practice and culture

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change was required before being able to implement The American College of Critical Care Medicine's Clinical Practice Guidelines for support of the family.⁶ Family centred care means sharing the responsibility of patient decision making with the family, incorporating effective and frequent communication with family as well as facilitation of family participation in care.⁷ Obvious benefits of family involvement in care include emotional and social support and comfort for the patient. Importantly, the family often knows the patient best, is the one constant throughout the critical illness experience and most often represents the patient's best interest. An emerging additional component of family centred care is the contribution to early detection of clinical deterioration whilst hospitalised, a central component of safety and quality in patient care.⁸

The Australian Commission on Safety and Quality in Health Care developed National Safety and Quality in Health Service (NSQHS) Standards to drive the implementation of safety and quality systems and improve quality of health care in Australia. The 10 NSQHS standards cover areas where it is known that patients experience higher levels of harm and there is evidence of how safer and better care can be provided.⁹ Since the standards were implemented in 2012 health services have initiated and enhanced safety and quality systems to ensure minimum standards of care that patients and families can expect. The Standard 2 "Partnering with Consumers" principle is that where health services promote partnering with patients and families, the safety and quality of patient care improves. The important role that families contribute to health care outcomes is emphasised throughout the NSQHS Standards, including in Standard 9, specifically focusing on recognition and response to deteriorating patients in hospital. Here family involvement is twofold; being informed about Rapid Response Systems (RRS) and being able to contribute to escalation of care. In the paediatric setting a family escalation of care process might seem straightforward and complementary to the family centred care philosophy. This paper will draw together the synergies between family centred care concepts, the NSQHS standards, particularly standard 9, and progress in developing a meaningful family initiated process for escalating care in the face of clinical deterioration with specific reference to paediatric acute care.

2. Family involvement in escalation of care

Families are being increasingly recognised as key stakeholders in patient safety⁸ and specifically in the context of RRS. Leading international health care organisations including the National Institute of Clinical Excellence,¹⁰ the Institute for Healthcare Improvement (IHI)¹¹ as well as the Australian Commission on Healthcare Standards⁹ have emphasised involving families in recognising and responding to patient deterioration. The basis is that although families, are not responsible for assessment of clinical changes in patient condition, their familiarity with their family member can enable them to recognise early subtle signs of deterioration. This move was founded in part by a number of prominent paediatric cases where health care professionals failed to appropriately respond to families' concerns with tragic outcomes.^{12,13}

In 2001, 18 month old Josie King died as a result of a series of errors at John Hopkins Medical Center in Baltimore, Maryland, USA where she was hospitalized for burns.¹⁴ Her mother Sorrell King recounted her experience at the national conference of the IHI (2002) where she explained how Josie's death was the result of a total breakdown in the hospital health system. Ms King's articulate explanation of her feelings of powerlessness and frustration when she tried to communicate her concerns to staff about her child's deterioration had a profound effect at this meeting and later when recounted at the IHI's national forum for the 100,000 Lives Campaign in 2004. One of the proposed interventions from this forum

was the introduction of RRS where Ms King added that parents be able to activate the RRS. The King family advocated for a communication process between parents and healthcare providers that accounted for the possibility of human and system error and to put in place additional safeguards. The Josie King Foundation funded the launch of a patient safety program that included a mechanism for a family member, visitor or patient to activate the hospital's RRS (Condition HELP), first at the Children's Hospital of Pittsburgh (2005) and later at John Hopkins Medical Center in 2007. Since then the Josie King Foundation has provided a public voice and funding for Condition HELP to be widely implemented in hospitals in both paediatric and adult settings across the USA.

In 2007 there was a similar case in Queensland, Australia where three year old Ryan Saunders died from undiagnosed sepsis despite his parents repeatedly voicing concerns to health professionals. Many deficiencies in the healthcare received by Ryan and his family were found to have occurred.¹² The coroners' recommendations prompted the Queensland Health Service to implement a state-wide patient, family or carer escalation of care policy; "Ryan's Rule" (see Fig. 1).¹⁵

Root cause analyses of these and many other cases, both within Australia and internationally in developed country healthcare systems, have identified that healthcare providers did not appropriately respond to or act upon families' concerns, resulting in patient deaths.^{12,13,16–19} Key take home messages have been; a failure to place patients and families first, a negative culture in hospitals, poor communication, inadequate clinical governance and ultimately loss of trust by the public.²⁰ As a result both policy and legislative changes have followed that detail approaches to overcome these deficiencies for early identification and response

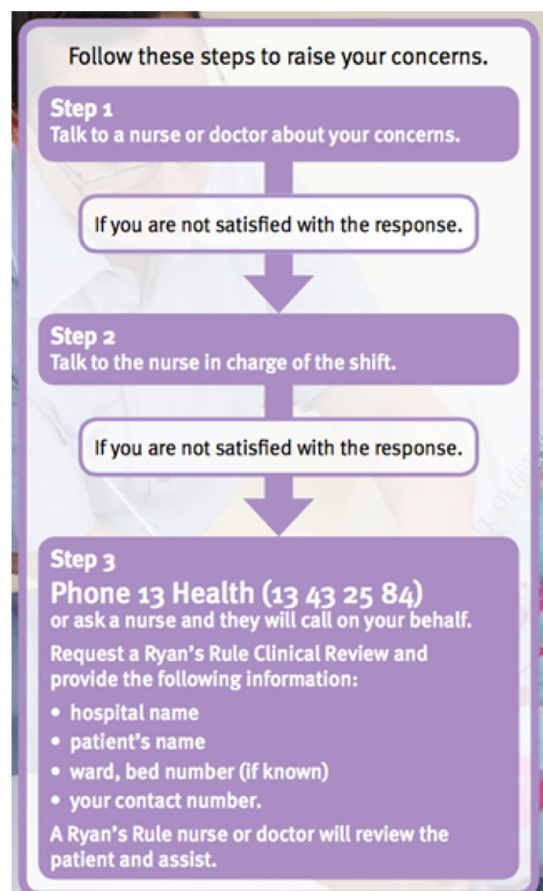


Fig. 1. Ryan's rule.
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